National Systems and Strategies for Provision of Care to HIV/AIDS Affected Adults and Children

By Susan Hunter, Ph.D.

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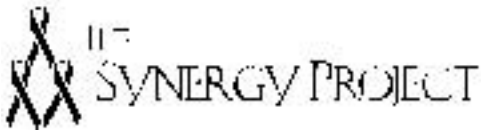

1101 Vermont Ave. NW
Suite 900
Washington, DC 20005
(202) 842-2939 phone
(202) 842-7646 fax
E-mail: synergy@tvtassociates.com
www.synergyaids.com

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Executive Summary

The growing size and complexity of funding for HIV/AIDS prevention and care programs from debt relief, World Bank IDA loans, and new grant options demand increasingly sophisticated program planning processes. Resource allocation requires critical decisions about target populations, programs, timetables and expenditure mechanisms, and the link of HIV/AIDS programs with broad poverty alleviation goals. Although planning processes become more complicated, formulation of good long term plans and strategies can increase the success of funding negotiations so that the largest possible amount of resources are leveraged.

Planning that improves the relationship between HIV/AIDS program expenditures and constructive long-term poverty alleviation can turn the tragedy of the pandemic into positive social action. The projected impact of HIV/AIDS means that heavily infected societies are faced with the task of building new, replacement, and compensatory social structures. The planning process provides the opportunity to rethink existing resource distribution and social welfare mechanisms so they achieve these broader social development goals.

In countries with severe HIV/AIDS epidemics, the disease is an extraordinary stressor that is transforming human social systems. Planning can create strategies that counteract the effects of this stressor, helping to ensure that resulting social change is positive over the long term. Effective strategies build on the embedded nature of social systems so that programs for HIV/AIDS-affected children, families and communities are linked not only with poverty alleviation programs but with programs in all other spheres.

Over the past 10 years, planning and strategy building in Sub-Saharan African countries has produced a rich experience in building social welfare systems that are strategic and take a long term, developmental perspective. Lessons from this experience tell us that community based systems are valued and valuable because they are culturally appropriate, low cost, and sustainable. They not only harvest the best of family and community experience in child care, but their development is the beginning of the healing process for this great tragedy of AIDS.

Supporting them with additional resources demands new ways of thinking and the wilingness to shape complex new social structures. It is in building them, however, that the beginnings of a new, post-AIDS society is fashioned. In this, the HIV/AIDS pandemic is fostering the development of a new relationship between African governments and the communities they serve. Recommendations for this purpose are found in the last section of this paper.

This paper summarizes the experience of Eastern and Southern African countries over the last decade in building replacement and compensatory social welfare mechanisms in response to the HIV/AIDS pandemic. The broad strategic framework described in this paper will expand the planning universe so that the most effective long term programs, reaching the largest number of beneficiaries, are established. It can also help generate criteria to guide NGO programs and grant making bodies so they serve broader State- initiated program decisions and strategies.

I. Introduction

The growing size and complexity of funding for HIV/AIDS prevention and care programs from debt relief, World Bank IDA loans, and new grant options from bilateral and private foundation sources demand increasingly sophisticated program planning processes. Resource allocation requires critical decisions about target populations, programs, timetables and expenditure mechanisms, and the link of HIV/AIDS programs with broad poverty alleviation goals. Although planning processes become more complicated, formulation of good long term plans and strategies can increase the success of funding negotiations so that the largest possible amount of resources are leveraged.

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The purpose of this paper is to summarize the experience of Eastern and Southern African countries over the last decade in building replacement and compensatory social welfare mechanisms in response to the HIV/AIDS pandemic. The broad strategic framework described in this paper, drawn from 11 years of experience in 14 Eastern and Southern African countries, will expand the planning universe so that the most effective long term programs, reaching the largest number of beneficiaries, are established. It can also help generate criteria to guide NGO programs and grant making bodies so they serve broader State-initiated program decisions and strategies.

Of the two broad categories into which HIV/AIDS programs are generally divided, prevention of HIV transmission and impact mitigation, this paper focuses on the latter, those that furnish care for persons with AIDS and their dependent survivors. Many of the details of programs for surviving children are contained in the companion document to this paper, ***Children on the Brink 2000***, and so are not described here. ***Children on the Brink 2000*** is a valuable resource for planning future programs because it contains current and future estimates of infection levels prepared by the U.S. Census Bureau, the only internationally recognized projections of HIV/AIDS trends. It also provides estimates and projections of the number of children who are and will be orphaned by the AIDS pandemic in 34 countries with severe epidemics.

II. The HIV/AIDS Pandemic Creates Major, Long Term Challenges

Several facts about the HIV/AIDS pandemic must inform any planning and resource allocation decisions:

1. ***The HIV/AIDS epidemics in countries with very high rates of infection in Eastern and Southern Africa are very long term social events***. When national infection levels rise above 15 and 20%, as they are currently in 8 countries and will be in 11 countries by 2010 according to the U.S. Census Bureau, they become self-perpetuating. Even if there were no new HIV infections after 2000:

a. *Infection rates will remain high through at least 2010*;

b. *Deaths will not level until after 2020*;

c. *The proportion of children orphaned will be unusually high through at least 2030.*

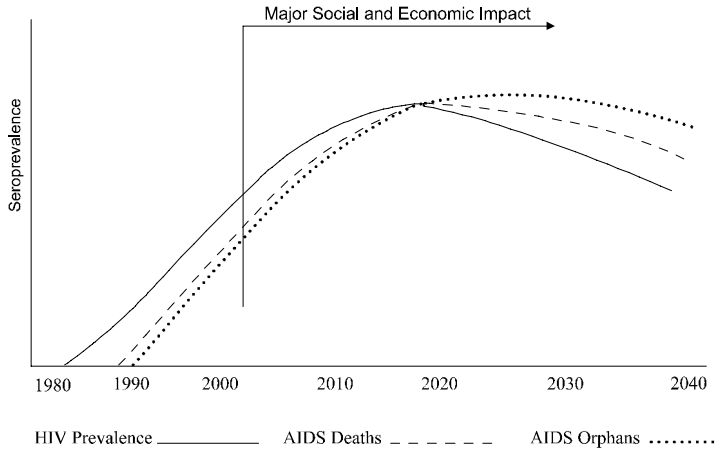
All of these facts make social planning critical, and require that social planning take a very long term perspective;

2. ***The scale of the challenges created by HIV/AIDS deaths is huge***. Between 20% and 30% of all children under age 15 in five countries with severe epidemics are currently orphans who have lost one or both parents to AIDS or other causes. By 2010, one fifth to more than one third of all children will be orphans in 11 countries included in ***Children on the Brink 2000***. These orphans, while important in themselves, also symbolize the significant social disruption and change to be faced by all countries with severe epidemics.

3. ***The problem is urgent***. Adult mortality is already at extremely high levels, ranging from two to five times higher than normal in areas with high infection levels. The mortality of children under 5, already much higher due to HIV transmission, may increase even more from other causes because of the loss of parental protection.

4. ***The loss of productive capacity to the pandemic will make it more difficult for countries to respond effectively***. Deaths of school teachers, health workers, and other critical professionals providing basic services are soaring above replacement level in many Eastern and Southern African countries. GNP loss is already substantial, threatening a spiral of increased deaths and poverty over the next decade.

Timing of Economic and Social Impact



Source: Hunter, ***Reshaping Societies***, 2000

Under these circumstances, good social planning, using expanded resources if they are made available, can mean the difference between growth and decay. How can we ensure that the former, not the latter, results from this unprecedented epidemic?

III. Developing Large Scale Systems for Impact Mitigation

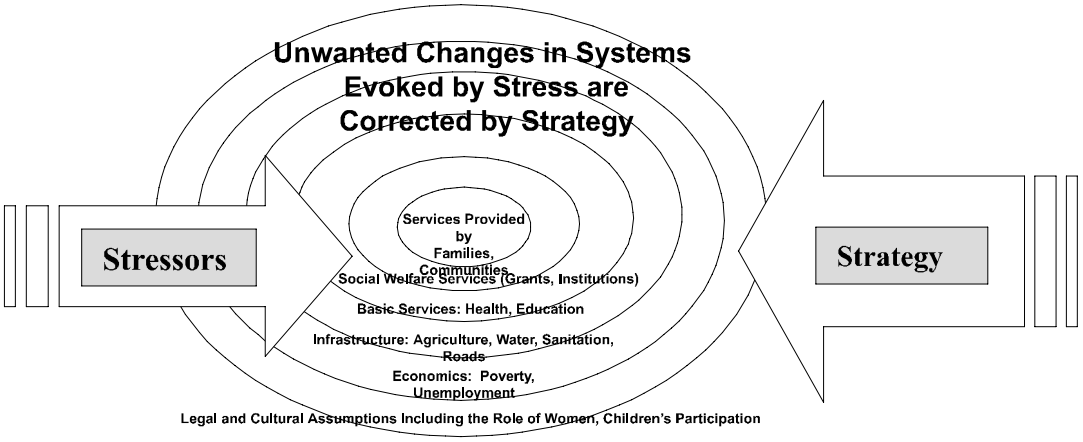
a. The Role of Strategy in Systems Evolution. When human beings live together, they **develop social systems or human infrastructure** to help them govern their relationships. These include economic systems, social systems, and political systems, the human and physical infrastructure, the methods and policies in place to deliver basic services and benefits. These systems support children as well as those providing care for adults and children affected by HIV/AIDS. Development of social systems for HIV/AIDS impact mitigation is a "work in progress"[1] in which strategy development has played a critical role.

Strategy is an overarching, multisectoral plan to meet the needs of large numbers of children, families and communities affected by HIV/AIDS over the next two to three decades. Most countries have one, although few are detailed. Some are well thought out and articulated multisectoral approaches evolved over a decade (Malawi, Uganda, Zimbabwe). Most are still evolving as policy makers and planners test different approaches. At least four countries in Eastern and Southern Africa had no articulated strategy for affected children and families at the end of 1998 (Lesotho, Swaziland, Tanzania, and Zambia).

System and strategy are separate concepts. There are national social welfare "systems" everywhere, even when they do not seem to be logical, rational, strategic or functional. There are systems that are growing without much government intervention or direction, and those that have been developed with firm exercise of government and NGO vision. And there are many countries without systemic underpinnings, lacking the resources and infrastructure for strategy implementation. Systems can be centralized or decentralized. Centralized systems function on the assumption that all or most benefits are provided by the State (Botswana, Namibia), while decentralized systems rely on individuals, families and communities to provide support (Uganda, Malawi, Zimbabwe). And there are systems intermediate to both extremes (South Africa).

Social welfare systems undergo change, following a **sequence of development** or **stages of evolution** that fall on a **continuum**. Because the social welfare system is interdependent with other human systems, each of these stages is associated with developments in other spheres of social support and community organization, and of nation building. Human social systems change because **stressors** arise from time to time that force them to change. Some stressors are negative, including wars, famines, and epidemics. The Convention on the Rights of the Child was a positive stressor that prompted many countries around the world to review their laws, enact new

legislation, codify old laws, and generate new concepts of family and community behavior. Some stressors are neutral, having positive or negative impact depending on how they are managed in different sectors, like computerization. Some are international in origin (colonialism, globalization), felt at the local level through national policies and programs. Some stressors are technological or human in origin, and most have a human component. Even "acts of God" are damaging only to the extent human systems have not planned for or anticipated their outcomes. HIV/AIDS is one of these.



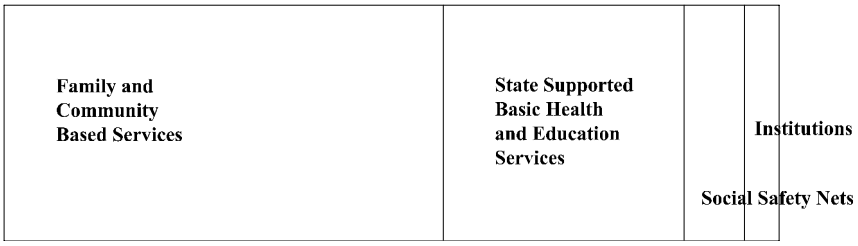
Strategy created in times of social stress and deployed to improve individual, family and community coping helps the social welfare system evolve to a more sophisticated level. Lack of strategy can lead to waste of resources, unnecessary loss of human life, and permanent social breakdown. As strategy evolves, the tools of policy and implementation must be consciously changed. For example, most countries in Sub Saharan Africa inherited adoption and fostering policies and laws from their colonial partners in the 1950's or 60's. The increase in AIDS-related adult deaths has prompted governments to reexamine old policies and laws governing formal and informal adoption and fostering.

Several countries have gone beyond simple changes in law. They are trying to raise awareness so that behavior changes and people are more willing to adopt or foster children. After the disaster in Rwanda in the mid-1990's, the government used the media to ask every Rwandan family to adopt an orphan. As a result, a majority of the children were provided a home. In the early 1990's, Malawi changed its adoption and fostering policies, and conducted a national media campaign to encourage fostering. It was swamped with responses from families eager to help.

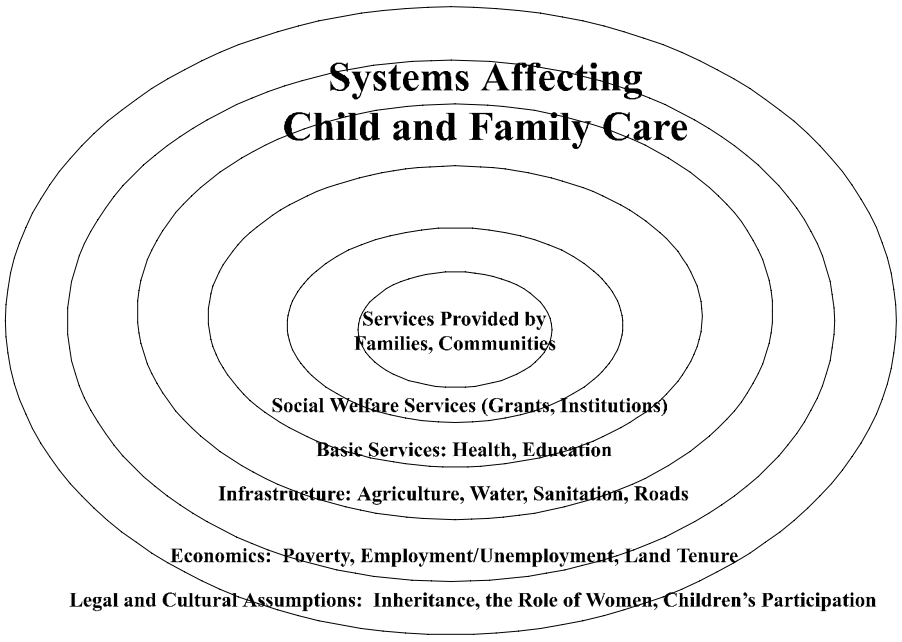
b. The Embedded Nature of Social Welfare Systems. Social welfare systems are multi-sectoral, but include four principal sources of support to AIDS-affected children and families:

1. Family and community based services
2. State or private education and health services
3. Social safety nets (old age and disability grants, fostering grants, food relief)
4. Institutions (orphanages, hospitals, prisons).

Social Welfare System Components



The welfare of children and families and the capacity and quality of services delivered by each component of the social welfare system are also dependent on the other human systems within which they are embedded:



From this perspective, provision of family and community based care for HIV/AIDS affected children and adults is comprised of and affected by:

1. A **core of direct services** provided by the family and community members;

2. **Direct benefits to the family or child** provided by State or private social welfare professionals, including those associated with NGOs or religious organizations, and in the case of home care services, State or private health professionals. Some children receive these benefits in an institutional setting;

3. Children and families also draw upon **health and education services** not specifically directed at HIV/AIDS, such as prenatal care, well baby care, immunizations, early childhood development centers, and primary education;

4. Availability of **infrastructure** determines the demand on individual, family and community labor to provide water, sanitation and food;

5. The surrounding **economic sphere** determines individual income, employment, credit, the distribution of income, the services provided by social systems as a whole, and the ability of the social welfare system to adapt to increasing demand for services through budget allocation, personnel training and administration, and benefits distribution;

6. **Cultural assumptions** (such as assumptions about the roles of women or the appropriate participation of children) circumscribe individual, family and community action.

As social welfare systems are built of these components, strategies for development attempt to:

1. Increase the quantity of services provided by each component;
2. Improve the quality of services provided by each component;
3. Change the balance of services delivered according to the capacities and competencies found within each basic component.

As society changes and each of these spheres expands or contracts, the demands on individuals, families and communities change. For example, as growth in infrastructure reduces demands on the labor of individuals and families to provide fuel, water and sanitation, the time available for childcare expands. As economies expand and provide more employment, individuals and families have more resources to provide care. If basic services in health and education are in place, there is less pressure on families and communities who are caring for chronically ill members or providing education and procuring health services for children.

As another illustration, there are many ways to "prevent" the incidence of orphans in society such as prevention of unwanted pregnancies, reduction in maternal mortality, prevention of HIV transmission, and support to persons living with HIV/AIDS to live longer. Most are outside the immediate purview of the family and community voluntary system and the social welfare system. Many of the most significant ways to "prevent" orphans are within the spheres of health systems and education systems. The most significant prevention strategies lie outside the sphere of basic services, such as improving economic opportunity, changing legislation to ensure the rights of women, children and people living with HIV/AIDS, and reducing poverty by increasing employment, business credit, and improving income distribution within a society.

Ways to "Prevent" Orphans

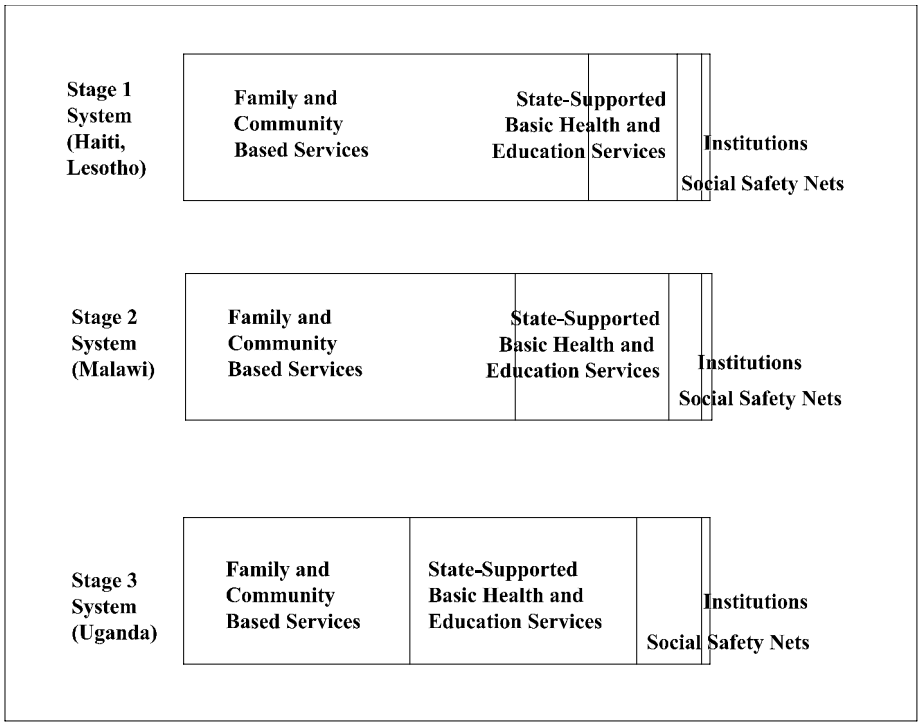
- **Reduce births**
  - Continue/intensify family planning education
  - Encourage directed counseling for HIV+ women considering pregnancy
  - Make family planning methods widely available, including barrier methods and condoms to prevent HIV transmission
- **Reduce maternal mortality**
  - Make family planning more available to reduce total fertility and associated ob/gyn problems
  - Improve women's access to health care services
  - Legalize abortions, reducing non-medical interventions
- **Prevent HIV transmission**
  - Make infection rates widely known
  - Make counseling and testing widely available
  - Provide widespread STD diagnosis and treatment
  - Encourage sexual behavior change
- **Support PLWHAs to live longer**
  - Reduce discrimination and stigma
  - Ensure access to medical care
  - Encourage good nutrition
  - Reduce stress, including concern about surviving children

In most countries with high HIV infection levels and growing AIDS deaths, individuals, families and communities are currently providing all or most care to HIV/AIDS affected children and families. Surveys in several countries show that few children or families benefit from direct social welfare benefits or from the work of social welfare professionals, and that most adults with AIDS receive care at home, not from hospitals. Families and communities also provide many of the health and education services received by children. HIV/AIDS challenges societies to change their balance of service delivery so families and communities with fewer adults are not overwhelmed by the growing responsibilities for child welfare. The chart on the next page highlights some essential changes in social systems that have occurred due to HIV/AIDS and other social forces in heavily-infected countries.

Changing System Characteristics in Heavily Affected Countries[2]

Systems Prior to HIV/AIDS	Systems with HIV/AIDS
Children	
‣ Social welfare provides for disabled children, children in trouble with the law, some street children, few orphans, adopted and fostered children	‣ Integrated systems of care are needed for many more orphans, abused and neglected children, more street children, adopted and fostered children, child headed households
‣ ***Number of vulnerable children in the thousands***	‣ ***Number of vulnerable children in the hundreds of thousands, millions***
Families	
‣ Most vulnerable children are cared for by families	‣ Families are less able to absorb vulnerable children (more children, greater poverty)
‣ Strong families exist	‣ Families are weaker
‣ ***10-20% of families with fostered children***	‣ ***50-75% of families with fostered children***
Communities	
‣ Customary law/authority is accepted	‣ Customary law/authority is weaker
‣ Churches have charitable activities	‣ Churches have community development and outreach services
‣ NGOs not numerous or active	‣ NGOs numerous, active, have a larger role
‣ Orphanages help 1 – 3% of orphans	‣ More orphanages but capacity is still low
‣ Few villages have active child and family welfare committees	‣ More and better organized village committees
‣ Public awareness low	‣ Public awareness high and growing
‣ Civil society is unconcerned	‣ Civil society is cooperative and active
Governments	
‣ The outreach of social services is low	‣ Social welfare professionals are overwhelmed and withdrawing
‣ No social safety nets or poverty alleviation programs	‣ Underfunded social safety nets and poverty alleviation programs
‣ Vertical, centralized programs	‣ Greater decentralization, growing integration
‣ Partnerships with communities and NGOs weak	‣ Partnerships with NGOs and local committees growing
‣ Direct government care	‣ Government-supported community care
‣ Basic health and education available	‣ Services constricted by cost sharing, budget cuts
‣ Economies and resources fairly strong	‣ Economies weakened; fewer resources
‣ Donor resources to governments	‣ More donor resources allocated to civil society
‣ ***Social worker to population in need: 1 to 10,000***	‣ ***Social worker to population in need: 1 to 100,000 to 600,000***
‣ ***Beneficiaries number in thousands***	‣ ***Potential beneficiaries number in millions***

c. Systems Change and the Balance of Service Delivery. Countries faced with the prospect of developing a rationalized system of care and protection for vulnerable children must optimize at least three aspects of the system: financial feasibility, availability of services and personnel, and acceptability. This can be done by improving the allocation of direct resources to children and families, or by increasing availability of goods and services in another component. These shifts in the balance of responsibility among system components occur as a result of changes in policy and their implementation, which may or may not be part of a rational strategy of systems development:



The stage of systems development in countries with severe HIV/AIDS epidemics varies. In the first stage of development, family and community based services are initiated indigenously and spontaneously, with no visible government strategy, and limited availability of basic health and education services. In the second stage, specific government policy favoring family and community based care has been articulated, a strategy is in place, and a national coordinating group has been formed to oversee its implementation country wide. Legal review has been initiated and is underway. To reduce the burden on family and community care givers, the government is consciously expanding basic services, and social welfare benefits are administered to some portion of the population. Institutional capacity has not expanded because families and communities are able to continue to absorb children.

In the third stage, the burden of family and community care has again been reduced by further expansion of basic service and unfettered access for fostering families. Basic services are integrating special care for individuals made vulnerable by the epidemic. Administration and funding are being decentralized, although professional social welfare services are still administered by the central government. Monitoring and evaluation are developed. Legal review for children has been completed, as well as a number of legal and policy changes in related sectors (women, marriage, property), and infrastructure is being expanded.

Through the process of systems development, governments bring social services system to scale. This is done by expanding family and community competency nationwide, and by complementary expansion of basic services, legal development, and expansion of infrastructure.

Characteristics of Country-Specific Systems Development

Country	Started	System	Requirements
Integrated, Decentralized Community-Based Service Delivery			
Uganda	1989	Integrated, decentralized, evolved from indigenous family and community based system; locally financed; policy in place	Resources at local level, monitoring to maintain quality of local social services delivery
Partially Integrated Community Based Systems			
Malawi	1992	Full fledged community based system with initial integration in education; centrally and locally financed; integrated into local development plans but not central; policy in place	Resources at national and local level, monitoring system, integration with health services, integration into national development plans
Zimbabwe	1992	Full fledged community based system integrated with social welfare but not health or education, centrally financed, policy under development	Resources at national and local level, monitoring system, integration with education and health services, integration into national development plans; complete policy review
Direct Support with Safety Net Structure			
South Africa	1994	Commitment to community based services, articulating policy and strategy; direct grants and services to families	National policy and strategy and all of the requirements for systems development shown for Zimbabwe
Nascent, Developing Community Based Systems			
Tanzania	1988	Reviving earlier community based system; policy in place; community competency built in community nutritional program	Resources, specific strategy for expansion of family and community care; policy review, integration with basic services
Mozambique	1996	Initial stages of community based system development; policy in place	Strategy, resources, development of basic services, integration, monitoring
Direct Support with Little or No Community Based Services			
Botswana	1990	Direct grants and services, strategies and policies for community based care unsure	Comprehensive development following Uganda, Malawi, Zimbabwe
Namibia	1994	Direct grants and services, strategies and policies for community based care unsure	Comprehensive development following Uganda, Malawi, Zimbabwe
NGO Driven Community Based Movement with Weak Government Policy			
Zambia	1990	No government policy or strategy; NGO-driven community based development	Comprehensive development following Uganda, Malawi, Zimbabwe
Swaziland	1998	No government policy or strategy; NGO strategy building started	Comprehensive development following Uganda, Malawi, Zimbabwe
Institution-Dominated System with No Government Policy			
Kenya		No government policy or strategy; NGO strategy building started	Comprehensive development following Uganda, Malawi, Zimbabwe
NGO Coordination, No System or Policy			
Lesotho	1997	No government policy or strategy; NGO strategy building started	Comprehensive development following Uganda, Malawi, Zimbabwe

In 1988 in the Lake Zone, Ugandans and Tanzanians worked side by side to develop systems of community based mutual assistance. Even before the development of donor interest in 1989, communities in the heavily infected Rakai District of Uganda and Kagera District of Tanzania organized themselves to identify and target vulnerable children of all types, provide cluster foster care, hold regular coordinating meetings and solicit outside donor support. They then taught neighboring communities how to organize themselves. Communities have acted to protect

women's property, starting in Tanzania in the early 1990's, when local leaders, as part of a self-help initiative in Kagera, revised their by-laws to prevent property snatching without due process. Their models were adopted in Malawi, Zambia and Zimbabwe in the early to mid-1990's, and form the basis of our thinking about community based care, and how it can be diffused systematically in a country.

Uganda has moved from a system almost totally reliant on family and community based care in 1990 to one that is almost fully integrated with basic health, education and services that are decentralized, managed and funded at the district and local levels. The change over the last 12 years has required changes in many other social systems, including large investments in health and education, infrastructure, economic development, and the status of women. In the 1980's, health and education services were almost non-existent, formal social welfare benefits did not exist, poverty was extreme, infrastructure was broken by years of war, and cultural constraints, including the low status of women, had fueled the spread of HIV through many districts. As conditions in all of these areas have improved, the delivery of social welfare services has evolved as well. The experience of heavily affected countries shows us that social welfare systems evolve along a continuum, in response to specific strategies for development.

IV. Planning to Optimize Systems of Care

a. Core Services. In many locations, a core, somewhat standard, set of family and community based services have spontaneously developed on which deliberately crafted systems of family and community based care can be modeled. In these systems, volunteers organized themselves to carry out four types of activities to help children and families:

1. **Gather Information**. Vulnerable children and families are identified by volunteer committees using enumeration (census taking), needs assessments and monitoring visits;
2. **Provide Assistance**. Volunteers organize assistance, targeting the vulnerable;
3. **Develop Resources**. The committee also develops resources using local fund raising, donations, sales of crops, craft sales, or support from external NGOs and donors;
4. **Increase Labor Productivity**. Communal approaches are used to increase agricultural productivity, to share labor and improve quality in child care, to provide vocational training, and develop income generating projects and credit schemes.

Most countries have articulated a national policy supporting the primacy of family and community based care because it optimizes use of financial resources, and available services and personnel. It also maximizes acceptability, because families and communities typically report their preference for maintaining children within normal systems of social support. However, most also say they will need financial and material supports, including access to basic social services for their children, because of two constraints: extreme underlying poverty, and the need to provide for additional children within the same resource base.

Support to family and community care is a "preventive" intervention because it maintains children in the most "normal" environments possible. To the extent that children fall through these levels of care, then preventive interventions are not functioning well. If the system is explicitly conceptualized, emphasis and investment are distributed proportionate to the number of children needing each type of care. Referral mechanisms are crucial among providers, and between providers and community volunteers, to ensure that vulnerable children and families gain access to needed services, and move smoothly from one component of the system to another, or between levels of one component.

The chart below shows an approximate distribution of children within a typical system of care in a developing country heavily impacted by HIV/AIDS. The estimated proportion of children cared for by each source of care shown in the third column will change over time as mortality from the AIDS pandemic increases. However, even in a very advanced epidemic, an estimated 55% of children will still be cared for within some form of family, while 35% of care will be provided by community organizations at some level of formal organization. Institutions at any time will provide care or at least shelter for no more than 5% of all children due to fiscal and physical constraints (i.e., the number of places within institutions), while some 5% of children will be in transit, assisted by temporary forms of care like street children's shelters, safe houses, or residential homes.

Models and Options in a System of Care for Vulnerable Children[3]

Option for Care	Responsible Party	% of Children	Needed Inputs and Supports
System as a whole	Government and partners	100%	Legal and policy framework Conceptual base Referral networks, monitoring, identification
Family Based Care	2 biological parents 1 biological parent Extended family Child headed households Formal foster parents Adoptive parents	55% .5 to 1% (with formal adoption)	Free access to basic social services Psychosocial support and monitoring Government assessment and monitoring
Community Care	Village Committees Local government Volunteers Community based organizations (CBO) NGOs, Religious organizations Private sector	35 %	Management training, financial and material support, training in psychosocial counseling, child rights training, monitoring and evaluation, awareness raising, advocacy
Temporary Shelters	Street children shelters, feeding centers, places of safety	5%	Management training Financial and material support Psychosocial counseling
Institutions	Orphanages, children's homes, hospices, hospitals remand homes, jails boarding schools	5%	Facility construction, equipment Guidelines, policies, standards Awareness raising Fostering and out-placement Counseling Community visiting CRC training Government assessment Monitoring and evaluation Fund raising skills Networking and outreach services
Social Safety Nets	Government and partners	1 to 10% of all children need grants (foster care, disability, old age pensions, stipends for care givers) 100% need free primary health care, free primary school, employment training, income generation, credit	Ministry Support: Finance, Social Welfare, Health, Education, Labor, Education, Private sector

b. Planning for the Most Numerous, Not the Most Visible. A certain proportion of children will fall outside of family and community based systems of care, and must be provided for by institutions, including orphanages, children's homes, and remand centers. Children will also need temporary shelters, where they can be provided care while in transit between one form of permanent care and another. For example, children leaving family based care may receive support at a street children's shelter or feeding center while they are rehabilitated for placement

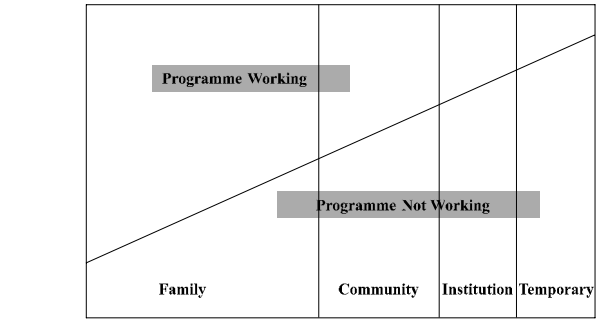
in another family or in a community care program. HIV/AIDS increases the number of vulnerable children, and the tendency of policy makers is to rush to provide care to the most visible children, who may or may not be the most vulnerable or numerous groups of children needing care. In the box above, the vertical axis describes vulnerability as "high" or "low", while the horizontal axis describes the number of children.

Number and Vulnerability of Children Needing Care and Protection

Vulnerability	Number of Children: HIGH	Number of Children: LOW
High	Very young orphans Orphans with disabilities Orphans with elderly guardians Children in female headed and poor households	HIV + children Street children Child sex workers Orphans in child headed households Children in under-funded State institutions
Low	Orphans in stable families of reasonable means	Children in stable families of reasonable means both parents Children in well-resourced institutions

The largest number of highly vulnerable children are in the upper left hand corner, and include very young orphans, orphans with disabilities, orphans with elderly guardians, and children in female headed and very poor households. Also highly vulnerable, and very visible because of that vulnerability, are HIV positive children, street children, child sex workers and orphans in child headed households. However, these are fewer in number than children in the left hand box. While a great deal of concern is expressed for HIV positive children, globally they represent only 1.7% of children affected by HIV/AIDS, while orphans represent more than 98% of affected children. This average is typical of most highly infected countries because most HIV positive children die before age 1. Children in poorly resourced institutions are also in this category because in many cases, their basic rights are not protected (Ahmed et al., 1999). Children who are highly vulnerable are likely to need the most safety nets and protection.

Children who are less vulnerable are shown in the bottom row of the chart. They include orphans and children with both biological parents in stable families of reasonable means. Children move between boxes — levels of vulnerability — depending on changes in their life circumstances. The AIDS pandemic increases the number of highly vulnera-



ble children in the upper boxes. Preventive interventions are successful if the number of children in the upper right hand box, those who are most vulnerable, is as small as possible.

The total number of vulnerable children is very difficult to estimate because of the probable overlap of vulnerable children in various categories. However, for purposes of estimation, it includes orphans not living at home, HIV positive children, children in female headed and foster families who are below poverty level, and street children. Children in HIV affected households, children in institutions, disabled children and children in conflict with the law are presumed to be included in other categories of vulnerability. Orphans not in families may be assumed to be in institutions or in the foster care of unrelated adults. Child domestic workers are assumed to be included among fostered children.

Vulnerable households include large households with fostered children; households below the poverty line; female headed or female managed households (poorer and more vulnerable than male headed households and more likely to be providing care for HIV/AIDS affected and infected adults and children); and rural households, (more likely to be without electricity, running water, and toilets). Poor sanitary conditions for children manifest in large numbers of cases of diarrhea and other gastrointestinal illnesses. Many orphans are cared for by their grandparents in households with high dependency ratios.

c. Complexity of Systems Options. To address problems of poverty, lack of basic services and resources, and ensure equity and expand coverage, existing infrastructure must serve the maximum number of people possible. Two factors constrain optimal systems design: lack of familiarity with alternatives and their relative complexity. The most expensive form of care, orphanages, are the least complex but most familiar. In some countries, accidents of charitable history mean that a very few children in select institutions receive as much assistance as all other vulnerable children combined. Orphanages were established following Western models when few children needed institutional care. In most countries institutional capacity is 1-3 % of total need, but in Haiti, where institutional growth has been unfettered, it is 7%.

Family and community based care, serving 93% to 99% of all children, is the least expensive but most complex because it requires family and community behavior change, discipline, and partners that know how to provide and organize support. Orphanages are less acceptable to families than community care because children have difficulties adjusting to social life when they leave institutions and can suffer loss of land, property, and contact with their families and traditions. Orphanages also divert resources from community care programs with long term poverty reduction potential. These approaches increase dependency on external sources of support with potentially disastrous consequences when they are withdrawn.

Family and community based approaches encourage community self- reliance, voluntary and spontaneous links with HIV/AIDS prevention activities, and build on the reality that People

Living With HIV/AIDS (PLWHA) and affected children get most of their support from their families and communities. Social workers and other professionals can focus on difficult cases, monitoring, training, and support. Community care delivers benefits more effectively and less expensively, and because it builds on the natural human preference to maintain children within their families and communities, fewer children fall through safety nets.

Complexity of Care and Experience

Type of Care	% of Vulnerable Children	Complexity	Experience	Cost Per Child
Institution	5%	Low – independently Operated	High	High
Temporary	5%	Low – independently operated	High	Medium to high
Family	55 – 65%	Community and national system needed to strengthen family behavior	Medium to low	Low
Community	25 – 35%	National and local systems needed to strengthen community caring behavior	Low; precedents in community development	Low

If decision-making criteria for systems design are not explicit, the shape of the system evolves in response to resource allocation. For example, institutions, because they are visible, often receive too large a share of government resources relative to the number of children for whom they provide care. This reduces the proportion of resources available to other options for care, especially family and community based care. Also, financial safety nets or grants may receive an inordinate amount of attention but provide assistance to relatively few families and be extraordinarily difficult to administer and monitor as the number of potential beneficiaries grows. If grants are provided, they might be provided through local authorities, NGOs or CBOs on a capitation basis to reduce administrative costs. At least one government is now considering this alternative.

d. What Country Experience Tells Us. To develop their social welfare systems, many heavily infected countries have decided to strengthen family and community based care because it is the most cost effective and acceptable approach. Their national implementation strategy recognized that in the short term (3-5 years), a national orphan program requires investment in program-specific services to:

1. Organize national, regional, and local coordinating committees;
2. Catalyze community organisations;
3. Develop networks of service providers;
4. Undertake legal review and policy changes;
5. Develop data collection, modeling and research capabilities;
6. Establish a monitoring and evaluation system;
7. Develop public and policy maker awareness;
8. Undertake fund raising for expanded programming.

Programming needs to be vertical and focussed until the ground work for long term response is made. It may take 10 years or longer to pass through the initial organizing stage because of multisectoral involvement. Even then, a country may wish to maintain a national policy body for advocacy, on-going monitoring, and policy and program development. Over the long term (5 —10 years), implementing agencies integrate family and community support programs into mainstream services in health, education, agriculture, water and sanitation.

The processes of strategy and policy development in Malawi, Uganda, South Africa, and Zimbabwe were linked with development of a managed, rational system of care and referral that supported community based initiatives. These systems were developed over a period of several years, following recognition by government that it would be unable to manage the child protection and care requirements of all orphans and vulnerable children as a consequence of the AIDS epidemic. Government and NGOs made a commitment to cooperate and collaborate to support community development and capacity building in order to provide care and support services for families and children affected by HIV/AIDS.

Roles in Malawi's and Zimbabwe's Systems of Care

Central, District, Local Government	NGOs Churches	Family and Community
Leadership	Training for families and communities	Provision of care
Stimulating collaboration	Capacity building	Mobilization and coordination of resources
Setting standards and guidelines using consultative process	Material support	Prevention of abuse, neglect
Monitoring community based groups to ensure child rights are protected	Provision of institutional care	Counseling for children, guardians
Handling cases requiring legal procedures	Mobilization of resources required by communities	Collective mutual support (labor, child care, credit, microenterprise farming and food security fund raising)
Helping communities obtain specialized resources		

The partners in these systems consciously acknowledged that formal social welfare, health and education systems established and developed through many years of experience prior to the epidemic would have to be fundamentally and conceptually revised because of the impact of the AIDS epidemic. Such recognition was not easy for any of the partners because it involved reconsideration of their traditional roles and responsibilities in child protection.

In Malawi, a 1999 review showed that after six years of development, community committees covered approximately 60% of the country, but needed substantial infusions of resources and technical support. Communities also believed that the following support would be essential to sustaining their committees:

1. Continued training in organization and leadership;
2. Training in child health monitoring;
3. Agricultural training and inputs (seeds, fertilizer) to increase food security;
4. Early childhood education centers for monitoring very young children.

Most communities did not ask for primary education or school fees because these are now being provided through universal free primary education, instituted in Malawi in 1997. However, many asked for support for secondary school fees, which they were providing through local fund raising and income generating activities. Most communities did not ask for cash or extensive material resources, a promising sign in a country with few resources to spare.

e. Government Safety Nets. Over the past decade, many governments in Sub Saharan Africa have been responding creatively and energetically to assist children, families and communities affected by HIV/AIDS. Countries have revised a variety of laws and created new policies to protect children. Judicial systems have been more flexible towards women and children defending their inheritance and rights to property. Land tenure systems and property ownership have been opened up to women in several countries (Mozambique, Namibia, and Tanzania). Uganda provides voluntary child advocates to help children redress exploitation. Uganda, Malawi, Zambia and Zimbabwe support village committees to assist children. Botswana, Malawi, Namibia, South Africa, and Zambia, among others, provide public welfare assistance and support to adopting and foster families but they are under-funded. Government safety nets include:

1. Adoption and fostering stipends provided to families caring for children up to the age of maturity, 18 years in most Eastern and Southern African countries;

2. Public welfare assistance grants provided to needy and vulnerable families, including those caring for AIDS patients, single mothers, disabled persons, and the elderly;

3. Services through health, education and social welfare systems, including primary care for mothers, children and for persons with infectious diseases; free schooling for all children or for orphans; and stipends and material assistance through social welfare for the education and health needs of poor children and families.

Community based systems can be developed and maintained at scale, but only if services in complementary sectors are expanded. A 1996 Zambian study showed that only 2% of the needy that qualify for support receive assistance (Hunter, Zambia 1998). A 1998 WHO study of Botswana's home care patients, entitled to government disability benefits, found they couldn't afford food (Hunter, Botswana 1998). Successful system-development recognized that the limited supply of social welfare officers was needed for triaged consultations with community committees, for training, and for monitoring quality of care. National coordination, policy

development, technical assistance and resource allocation were essential to bring systems to scale, and to identify and address geographic and programmatic gaps in service delivery. This is not to say that all systems are currently providing services to all vulnerable children, but rather that a strategy for achieving this is being pursued.

Analysis of specific legal provisions and distribution of benefits present a different picture than legal entitlements. In South Africa, the Women's and Children's Budget Initiatives found that while the law provides many benefits to women and children, they were limited by budgetary and administrative constraints (Institute for Democracy in South Africa, 1996). In Botswana, female headed households (47% of the total) form the majority of households living in poverty. These households are also more likely to be taking care of AIDS infected adults and their children but have less access to services (Botswana National AIDS Control Programme, 1996).

Many African governments have spent considerable time and resources designing and building social welfare systems that provide services and support to the elderly, the disabled, and the needy. These systems were originally designed and budgeted to help several thousand beneficiaries, mostly the elderly. Social welfare systems were designed to address the needs of relatively few numbers of vulnerable children who fell outside systems of family care. Cuts in social spending in most developing countries have led governments to rely on poor communities to provide social services for themselves on a voluntary basis. Volunteer groups are expected to function as major social welfare systems, providing services in health, education and public welfare support. While these were working prior to HIV/AIDS, the increasing burden of care must be examined to determine support needs of volunteers. In many cases no one is monitoring them systematically to see how long they can sustain the burden or if they are being effective.

Deficiencies in Social Welfare Services in HIV/AIDS-Affected Countries

- No benefits or grants to vulnerable populations
- If entitlements exist, budgets are insufficient for benefits promised
- Social welfare officer to population ratios very low
- Administrative bottlenecks and paperwork complex
- Casework approach to benefits distribution
- Benefits financed by NGOs and foreign development assistance
- Lack of basic health and education services means families and communities provide basic care
- HIV/AIDS not recognized as a disability
- Data needed to create realistic strategies
- Donors need strong direction consistent with national policy
- Coverage data is poor
- Support goes to self-identified families and is urban biased

They are now faced with serving very large numbers of children and the vulnerable elderly. In most Eastern and Southern African countries, social welfare comprises less than 1% of the national budget. Social worker to population ratios are as high as 1 to 1.2 million. This pressure creates common problems:

1. Budgets are insufficient for benefits promised;

2. The number of personnel required to distribute benefits is insufficient. Most countries have social worker to population ratios of 1 to 100,000 or greater;

3. HIV/AIDS need to be recognized as a cause of disability. Botswana and several other countries have identified people living with HIV/AIDS as disabled persons eligible for special government grants;

4. A casework approach to benefit distribution prevails, requiring lots of paperwork. Massive increase in demand for social welfare services has created bottlenecks or denials of entitlements to persons living with HIV/AIDS and children vulnerable to the epidemic;

5. Governments rely on NGOs and donors to fund benefits and provide systems for their distribution;

6. Lack of free universal primary education and primary health care means that social welfare benefits are used to pay school fees or health charges;

7. Lack of AIDS data and data on families and children has contributed to development of unrealistic strategies of assistance or to a general lack of preparedness in many countries.

8. Governments are overrun by well-intentioned donors needing strong direction. For example, many people want to donate to or develop orphanages, but they are costly, inefficient, and less acceptable than community care on the large scale.

9. Support goes to self-identified families, and is urban biased.

10. Coverage data are poor for all social services, obscuring the true situation of vulnerable children and families. When coupled with lack of information on seroprevalence, the ability of Ministries to articulate the issues and to plan and budget for adequate services is severely limited. This deficiency is being addressed by service inventories in several countries.

V. Strategy Development and Systems Change

a. Strategic Foundation. While it is not possible to reverse increased HIV/AIDS-related deaths and illnesses for children and adults in countries with severe epidemics, it is possible to change existing social welfare systems to reduce unnecessary infections, deaths, or illnesses, and other adverse consequences. Most countries are developing strategies, changing their social welfare systems and related basic services, building infrastructure, and strengthening poverty alleviation programs. All hope to provide more care and lessen the damage to future generations. Strategic actions include:

1. Planning Process. A national, multisectoral strategic planning process with systems building and technical components, based on a competent **situation analysis**[4];

2. Collaboration. The magnitude of impact requires that all potential actors be enlisted early and involved in an open and collaborative planning process;

3. Stronger strategic direction is needed to evaluate the extent of coverage provided by voluntary mechanisms, basic health and education services, and safety nets in guaranteeing the basic survival and protection of very young children and children in child headed households;

4. Estimates and Projections. The demographic impact of HIV/AIDS and prevailing social and economic conditions are being researched so that needs can be projected more intelligently at the national and subnational levels;

5. Substitute social protection mechanisms and compensatory measures for vulnerable children and families are now being implemented in heavily infected countries to avert the need for large-scale relief activities for some years to come;

6. Government and private partners are concerned that **basic survival needs** continue to be met because conditions are returning to those of the 1960's. Health, education, and social welfare capacity in Sub-Saharan Africa must be maintained and increased, if possible, to manage the pandemic's impact;

7. Endogenous Coping, Exogenous Strategies of Support. Understanding how children, families and communities are coping helps tailor external assistance to be more supportive. The table on the next page summarizes endogenous strategies, those developed by children, families and communities themselves, and the third the exogenous, or external, strategies of support derived from the 13 countries visited;

Aligning Exogenous Support with Endogenous Coping Strategies

Level	Endogenous Coping Strategies	Exogenous Support Strategy
Children and Young People	‣ Children try to optimize their migration among families for economic and emotional reasons, sometimes overriding adult decisions about their care givers	‣ Psychosocial counseling, economic support
	‣ Children scavenge for resources/food in resource poor settings	‣ Food relief in school, social centers, MCH clinics
	‣ Children identify and target needy children	‣ Include children on volunteer committees
	‣ Children share resources with other children	‣ Enlist children's clubs to help
	‣ Siblings provide and care for their brothers and sisters	‣ Economic and food support to child headed households
	‣ Siblings try to stay together	‣ Economic and food support to fostering households
	‣ Children try to remain in their homes and communities	‣ Protect widows' and orphans' property rights
	‣ Children try to stay in school or get vocational training	‣ Free universal primary education and vocational training
	‣ Children engage in sex work to pay for their basic needs or those of siblings	‣ Economic programs targeting children and young people
Families, Households	‣ Families optimize distribution of children to match resource availability	‣ Target benefits to children, not families, dying parents should know their status to prepare their families for death
	‣ Families provide most of the aid, few receive support from community or State	‣ Economic and food support to fostering households, income generating projects
	‣ Families identify sources of support by themselves	‣ Use media to advertise available support
	‣ Many extended family members accept children but are not happy with the burden and expect support	‣ Economic and food support to fostering households, psychosocial counseling by volunteers
	‣ Care givers are often elderly women	‣ Economic and food support to fostering households, assistance with household tasks, pensions for the elderly
	‣ Family members sell capital goods, livestock and land to provide care	‣ Economic and food support to fostering households, agricultural assistance
	‣ Families cope with food shortages by not eating, nutrition poor especially in families with HIV/AIDS	
	‣ Families cope with cash shortages by removing children from school	‣ Free universal primary education, labor saving interventions (water, sanitation, fuel, agriculture)
	‣ Families try to cope with death by taking a stoic attitude	‣ Voluntary psychosocial counseling, monitoring system to prevent abuse
	‣ Families favor biological children in the distribution of resources	‣ Psychosocial counseling, target benefits to children, not families, widen availability of basic health and education services, public education
Communities	‣ Support systems build on traditional forms of organization and mutual aid	‣ Train communities in self organization, data collection, and monitoring
	‣ Changing rituals as deaths become more common	‣ Voluntary psychosocial counseling
	‣ Communities receiving support have strong leadership	‣ Train communities in self organization, data collection, and monitoring
	‣ Support systems are fragile	‣ Include communities in official State social

Level	Endogenous Coping Strategies	Exogenous Support Strategy
		service systems, coordinating referrals and include them in systems of triage to professional help
	‣ Distribution of community support is ad hoc and equitable, but conditioned by overall availability of resources	‣ Support communities with material inputs, increase availability of basic health and education services
National Governments	‣ Pursuing new strategies	‣ Learn what other countries are doing to increase range of options
	‣ Laissez faire attitude on systems development	‣ Study the impact of HIV/AIDS and planning approaches to alleviate negative impacts
	‣ Future status of social welfare, health and education uncertain	‣ Make projections, conduct impact assessments, policy reviews, and barrier assessments
	‣ Coordination and cooperation of support systems is not strong	‣ Support coordinating mechanisms that include NGOs, local governments, village volunteers, and private commercial sector providers
	‣ Community care breaking down because families have to provide too many services	‣ Reconsider policies on financing to provide basic health and education services, develop infrastructure in water, sanitation, agriculture, provide State grants directly to families or to community groups under a capitation system
	‣ Concern with equity of benefit distribution	‣ Strategic planning to ensure geographic coverage, sectoral and barrier assessments, material support to communities, volunteer training in counseling, health, education services, conscious review of resource allocation to ensure equity in geographic distribution
	‣ Resources to expand availability of services scarce and insufficient	‣ Lobbying for debt relief
	‣ Leadership and policy is urgently needed	‣ Technical training for government leaders, collaborative planning, regional planning and study
International Partners	‣ Ensure soundness and equity of systems change	‣ Thorough situation analyses and technical models and training
	‣ Develop indicators and cost analyses to evaluate effectiveness of interventions	‣ Operations research, large scale economic models of inputs and outcomes
	‣ Develop mechanisms to channel aid directly to communities and small organizations	‣ Mirocredit, lending, investment in community groups' enterprises, trusts for development
	‣ Review policies of cost sharing	‣ Data and analysis, review past experience on cost sharing and recovery developed before AIDS
	‣ Reduce the crippling financial drain of debt burden on countries so they can improve services and infrastructure	‣ Debt relief, debt forgiveness, increased overseas development allocations, trade agreements

b. Strategic Capacity. The dilemma of large numbers of orphans and other children made vulnerable by the epidemic and relatively weak and poorly distributed services found in most countries suggests that explicit strategies are badly needed to develop existing social welfare systems. Capacity for strategy development is required along several dimensions: leadership and conceptual capacity, technical analyses, legal and policy reviews, and advocacy and public education.

1. **Leadership and Conceptual Capacity**. The vision of good leadership and development of the intellectual capacity for strategy development and systems design is critical and can be consciously cultivated. At the national level, development of strategies and systems require that national policy makers visualize and redesign existing systems in a fresh and innovative way. The meaning of social welfare must be entirely reconceptualized, moving from individual case work to community-driven systems of voluntary mutual support linked in formal triage to professional social welfare services. Social welfare professionals in many countries had already made this paradigm shift in response to budget cuts, and have been initiating curriculum and program changes to implement community based services. Expanded conceptual capacity was being increased through site visits and regular cross border meetings of policy makers and innovative community development personnel.

To support expanded conceptual capacity at the micro level, social welfare training has to be changed to increase the training of professionals in community development, AIDS-related psychosocial counseling, and techniques for training family and community members. Commitment to family and community based systems of care also implies "deprofessionalization" and "demystification" of some social welfare, education, and health roles, an appropriate policy for governments facing loss of professionals to HIV/AIDS.

2. **Technical Analyses**. Three types of technical data are needed:

a. **Estimates of persons needing care and of orphans and other vulnerable children**, available from National AIDS Control Programs and other sources[5];

b. **Sectoral analyses**, including impact assessments (supply, demand, cost, quality of service delivery), and barrier assessments. Ideally, each line Ministry can complete its own **impact assessment**, estimating loss of personnel and reductions in their client base caused by the epidemic, using population projections that include AIDS mortality. A few countries have completed an impact assessment for the Ministry of Health and many countries have evaluated the impact of HIV/AIDS on subsistence agriculture with FAO assistance. However, to change the social welfare system for AIDS affected children and families, sectoral analyses for education and social welfare are needed. Models are available from experienced countries (Swaziland Ministry of Education, 1999; Barnett and Whiteside, 1996; Roseberry, 1998; Ainsworth and Over, 1992; Drinkwater, 1993). In addition, line Ministry managers need to conduct a **barrier analysis**, brainstorming about epidemic impact so they are prepared to meet the needs of orphans. Barrier analyses identify policies and programs that limit access of AIDS affected children to services, and possible strategic actions. When these analyses are merged, an overview of geographic and safety net gaps will emerge. In many sectors, the presence of orphans will demand a change not only in scale of delivery but in the mechanisms of delivery of services.

Areas for Policy Review

Local Policy Review

- Allocation of land and other resources
- Communal gardens or shelters for children
- Sharing resources with the weaker and more vulnerable
- Use of local services by the poor or disenfranchised
- Participation of women and children in decision making
- Protection of women's and children's property
- Credit associations and small business opportunities
- Widow inheritance and mistreatment of children
- Community responsibility for all vulnerable children
- Interventions with harsh or abusive guardians

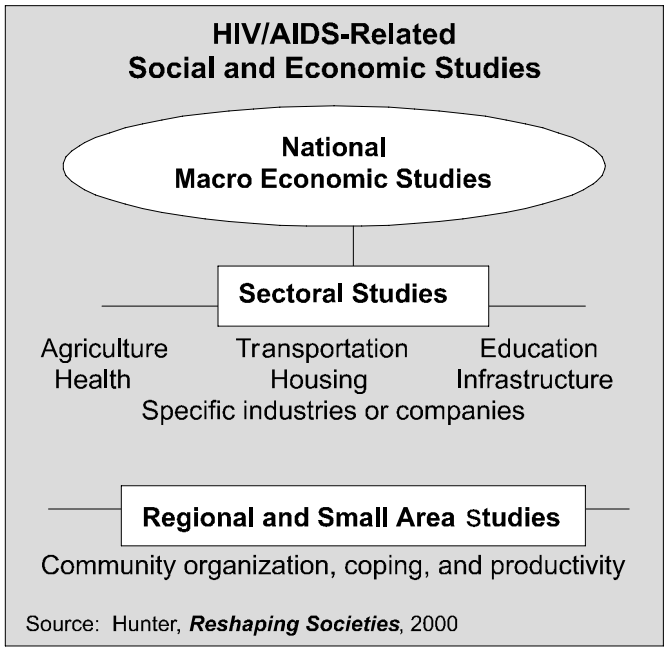
National Policy Review

- Review of laws, policies and administration in all sectors to protect child rights
- Children's access to resources without adults
- Increasing women's rights, entitlements and protection
- Recognizing legal maturity for women
- Definition of sexual maturity, age of marriage and defilement
- Entitlement and access of vulnerable children to health and education
- Budget restrictions, discrimination, or insensitivity
- Inheritance and protection of property
- Adoption and fostering
- Paternal affiliation and responsibility
- Public education programs
- Grants or other fiscal support to maintain children
- Positive support for communities
- Support to NGOs and CBOs
- Responsibility of the private sector
- Tax breaks to large private sector employers
- Employee rights, insurance and death benefits
- Targeting productive infrastructure to AIDS-affected communities
- Technical assistance to communities
- Support to increase productivity in agriculture or in small businesses
- Mechanisms to coordinating actors and partners
- Donors examine their policies

c. **Policy assessments.** Many countries have completed some parts of comprehensive legal and policy review for children as part of the development of their National Plans of Action for Children, stimulated by the World Summit for Children. Others have gone much further in codifying law for children and developing child and youth friendly judicial and ombudsmen systems. Uganda's Children's Statute is the most comprehensive and revolutionary of these legal frameworks. These reviews must be extended to account for the impact of HIV/AIDS on children and families. Only two countries in Eastern and Southern Africa (Malawi and Zimbabwe) have a specific national orphan policy, but neither had been formally adopted by Parliament because they promised additional resources to support affected children and families. Others are undertaking legal review.

Systems change occurs when actors at the international, national and local levels are not only committed to assist vulnerable children and families, but they put necessary structures in place to see that programs are implemented. A thorough policy review can stimulate change. It includes in many areas the laws and policies of government and other organizations like churches, NGOs, the commercial private sector and labor organizations. The policy assessment determines if policies take the needs of orphans and other vulnerable children, families and communities into account, and aims for better coordination of policies in different sectors so

they have stronger synergistic effects, and create an enabling environment for family and community based responses. This will promote mainstreaming of benefits and services.



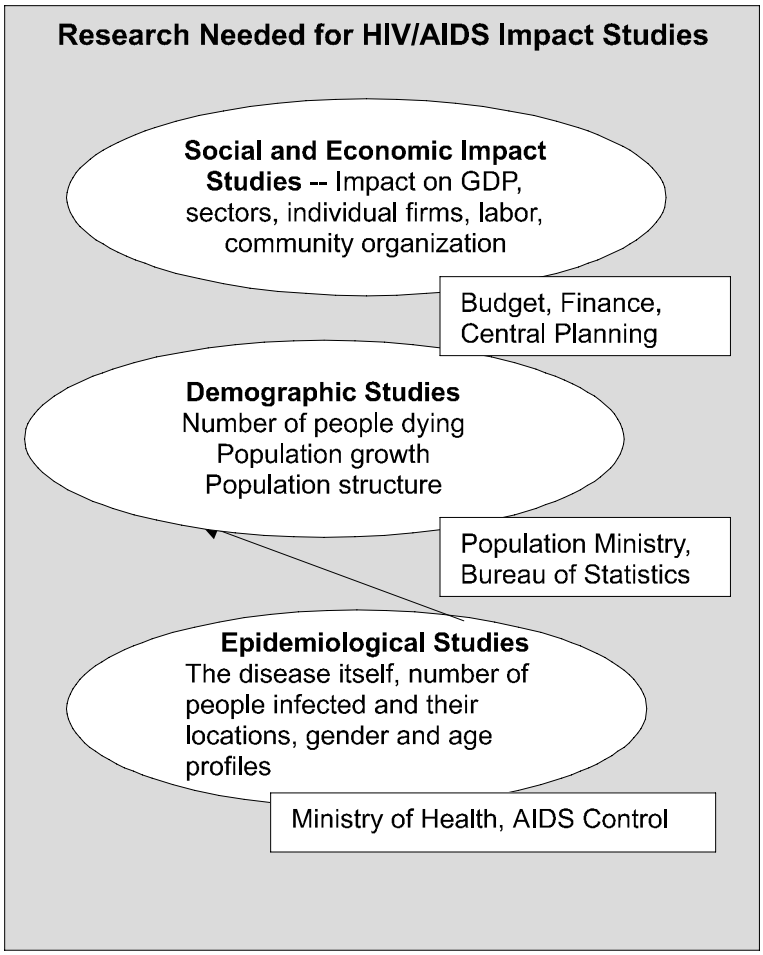
3. Socio-Economic Impact Analysis. It is inevitable that an epidemiological and demographic event the size of the HIV/AIDS pandemic will have significant impact on the social and economic life of countries with high infection levels and AIDS-related deaths. The pandemic is already having grave and immediate effects in all heavily infected countries in Sub-Saharan Africa, many not yet estimated or measured. Since changes in the epidemiology of HIV/AIDS are unlikely over the next decade, it is fair to assume that social and economic conditions will not stabilize for at least another decade. Effects may continue to be experienced for another two decades after that because populations and human systems will require considerable time for recovery. Not all changes will be negative, and a good number of positive changes have already been seen at the community level.
The tools needed to counteract the social and economic effects of HIV/AIDS are improving rapidly, and have been applied in several heavily infected countries. However, the amount of attention paid to these subjects is surprisingly small given their importance to survival and development over the next few decades. As more work in this area is done, our understanding of the current and future impact of the pandemic will improve radically. Several kinds of studies have been completed:

1. Studies of macro economic impact or aggregate impact of HIV/AIDS on national economic structure, inputs and outputs.;

2. Studies measuring the effects of HIV/AIDS on specific sectors (eg., health services, education, roads, agriculture); and

3. Studies measuring the effects of HIV/AIDS on specific industries or companies;

4. Studies of the effects of HIV/AIDS on community and household organization, coping and productivity.



Studies in each of these categories have been primarily quantitative, but an important aspect of each, with the possible exception of the macroeconomic impact studies, would require qualitative techniques and measures.

All social and economic studies have at their base, estimates of demographic impact, or changes in the size and age structure of the population. In turn, these demographic studies depend on epidemiological studies of the level of HIV/AIDS and other diseases in the population and their clinical effects on individuals. However, the logical relationship of each area of research is not necessarily followed in development of national plans, and studies of various types are not linked, even in the same country. So far, few countries have even projected the future course of their own HIV/AIDS epidemics, or estimated the impact of HIV/AIDS on their future population size, age and sex composition.

Many macro level studies are also not linked to, or widely shared with, sectoral Ministries. There are several reasons for these discontinuities. Often, the responsibility for each of these areas of research is in different ministries or departments, and they do not regularly coordinate their work. Second, macro economic research is often conducted by outside researchers, who may not be interested in or able to build capacity in the relevant ministries to continue this kind of modeling. As more countries develop the capability for multisectoral HIV/AIDS planning and epidemic management, some of these problems may disappear with increased communication. Also, as more HIV and AIDS data become available, it is possible to do impact studies that are more accurate and wider-reaching so more ministries can better understand the relevancy of this "health" issue for their work and their country's future. A general format for linking social and economic impact analyses is shown on pages 31 and 32.

Major work on modeling the impact of HIV/AIDS has been completed by two organizations, the World Bank and The Futures Group International. The Futures Group has developed a series of models, the Spectrum System of Policy Models, that includes sectoral modeling capabilities. Futures encourages links between ministries in different sectors when it begins a national modeling process, and also provides assistance with capacity building. The Spectrum System includes epidemiological and demographic projection models for developing a range of projection scenarios. The system can be accessed at no charge from The Futures Group web site (tfgi.com), and includes a series of extremely informative models that describe basic techniques in epidemiological, demographic and economic modeling.

VI. Strategic and Program Recommendations

In countries with severe HIV/AIDS epidemics, the disease is an extraordinary stressor that is transforming human social systems. Planning can create strategies that counteract the effects of this stressor, helping to ensure that resulting social change is positive over the long term. Effective strategies build on the embedded nature of social systems so that programs for HIV/AIDS affected children, families and communities are linked not only with poverty alleviation programs but with programs in all other spheres.

Over the past 10 years, planning and strategy building in Sub-Saharan African countries has produced a rich experience in building social welfare systems that are strategic and have a long term, developmental perspective. Lessons from this experience tell us that community based systems are valued and valuable because they are culturally appropriate, low cost, and sustainable. They not only harvest the best of family and community experience in child care, but their development is the beginning of the healing process for this great tragedy of AIDS.

Supporting them with additional resources demands new ways of thinking and the willingness to shape complex new social structures. It is in building them, however, that the beginnings of a new, post-AIDS society is shaped. In this, the HIV/AIDS pandemic is fostering the development of a new relationship between African governments and the communities they serve.

a. Strategic Recommendations

Several strategic recommendations can be drawn from existing African experience with the pandemic:

1. The long term demographic impact of the epidemic can be modeled by individual country planning teams. This modeling can feed a series of projection models by sector, showing the impact of the epidemic on supply and demand.

2. Policy makers in each sector should be encouraged and assisted to model impact through a participative process that includes impact, barrier and policy assessments so they are better equipped to do broad-minded social planning. The impact of the epidemic upon the ranks of health service providers, teachers and the military are three examples.

3. These sectoral models can be combined into overal economic impact analyses that better project the effects of the pandemic on GNP growth and resource distribution, including impact on poverty.

b. Program Recommendations

Supporting capacity building required for long term family and community based care reinforces the development process and provides the most promising opportunity for linking programming for HIV/AIDS prevention and care with poverty alleviation programs. This support can be achieved in several ways:

1. Expanding provision of basic social services and infrastructure in water and sanitation to lighten the family and community care burden;

2. Providing direct subsidies to care givers through foster and adoption grants. These can be distributed:

a. directly by the State, requiring extensive and time-consuming expansion of the administrative and professional structures, or

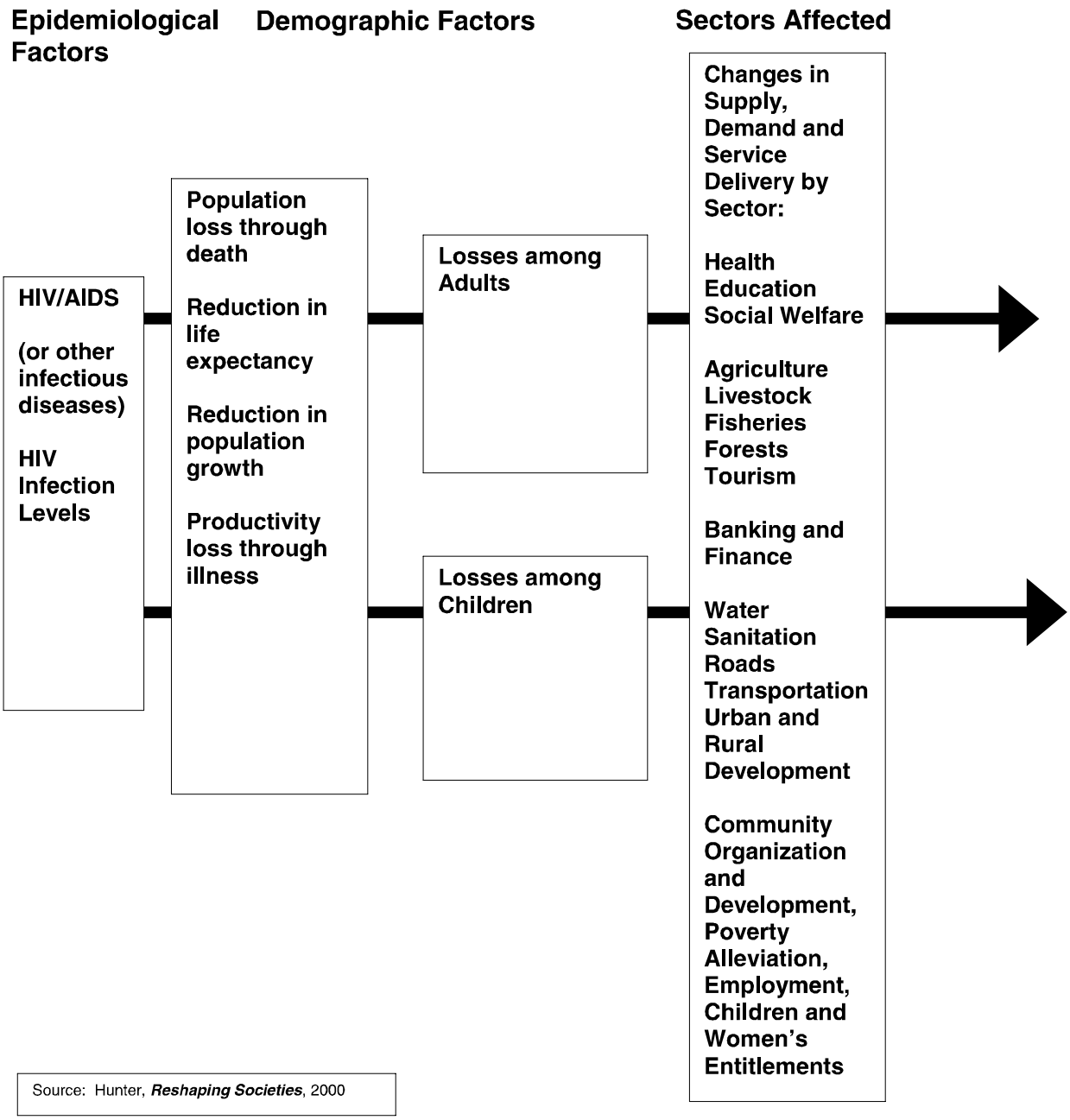
b. through NGOs and CBOs (community based organizations) using a capitation-based system whereby the organization is given a block grant which it distributes to eligible children, care-givers or families.

3. Providing development grants to communities that encourage existing positive coping behavior, like communal gardens and day care centers, through social action funds.

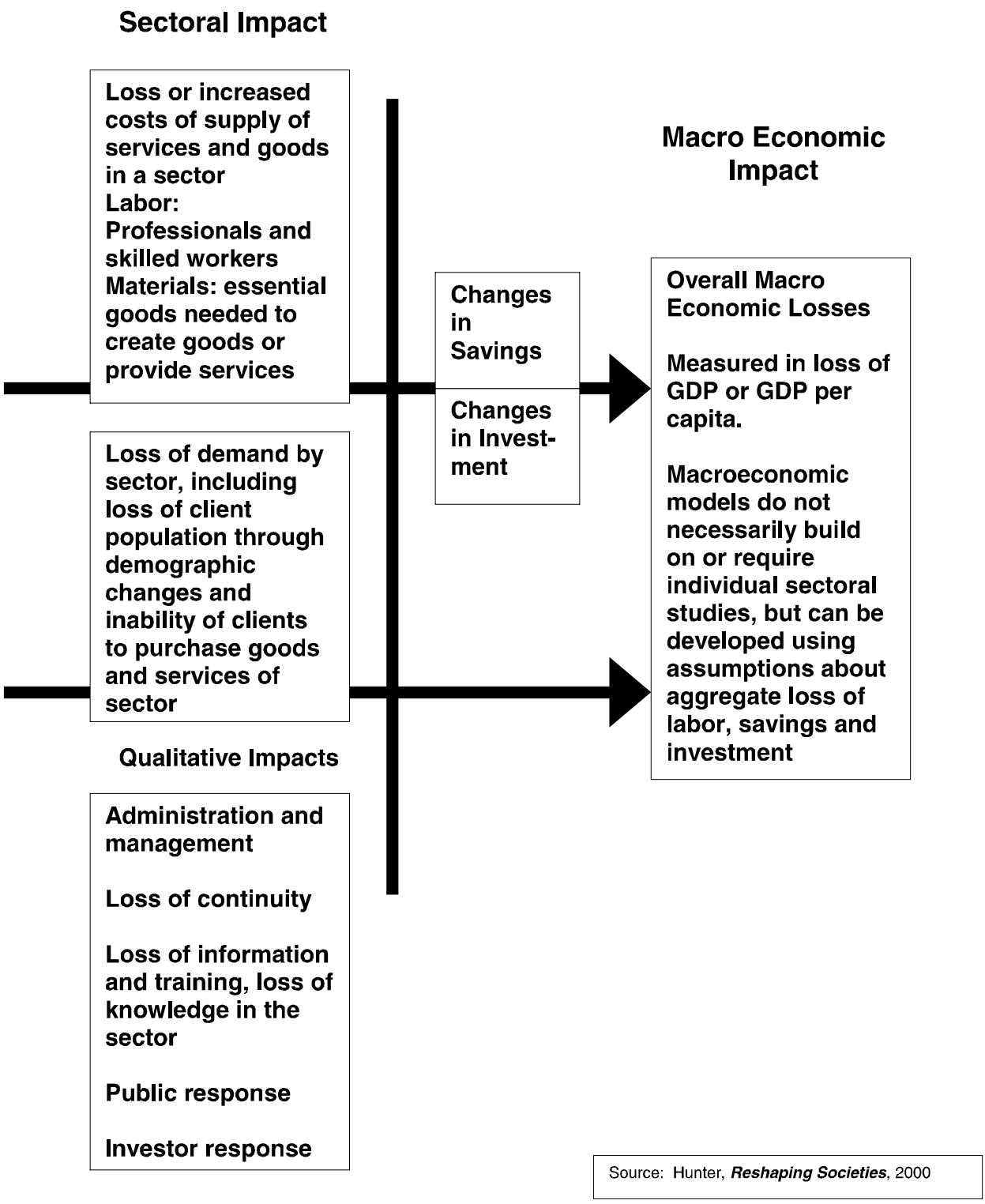
4. Expanding assistance and inputs to make agriculture more productive, such as credit, seeds, fertilizers, and extension services.

5. Coping with the impact of the epidemic by creating expanded employment in basic services for new cadres of community-based para-professionals who can provide outreach services and support to children, families and communities. This means that roles created by volunteer care givers and community organizers are formalized into employment so their work can be sustained and improved, and, more importantly, rewarded and recognized.

Levels of Analysis in Social and Economic Impact Analysis



Source: Hunter, ***Reshaping Societies***, 2000



Source: Hunter, ***Reshaping Societies***, 2000

Attachment: Indicators for Orphan Care Programs

A framework for developing program indicators for orphan care programs is shown on pages 35 and 36. It is divided into several levels to correspond to the type of indicator being measured: impact, outcome, output, or input.

Impact indicators

The measure of success of a program for orphans and other vulnerable children is how well it contributes to maintaining the well being of orphans and other vulnerable children relative to the "control group", non-orphans, on two commonly accepted indicators of children's well being:

Infant mortality rate - deaths per 1000, 0 to 12 months (orphans, non-orphans)
Child mortality rate - deaths per 1000, 1 to 5 years (orphans, non-orphans)

Since orphans and other vulnerable children are a significant proportion of the total population of children in countries with severe epidemics, these indicators would help mainstream programs over the long term. There are three other advantages: 1) these indicators are believed to reflect overall child well being and the well being of society as a whole, 2) they are widely measured, and 3) they would be a component of the comparative indicator suggested above.

Outcome Indicators. There are a whole series of outcome indicators for projects for orphans and other vulnerable children shown in the second tier of the chart on the following page. These include **education indicators**, like the percent of orphans that attend school and the proportion of female to male orphans attending school; **health indicators**, including those for immunizations and nutrition; support-related indicators for older children, including vocation training and access to employment; and those related to **living arrangements, care and protection**. These indicators are the result of program or project services, and also result from project activities that affect availability of government or NGO basic services for children.

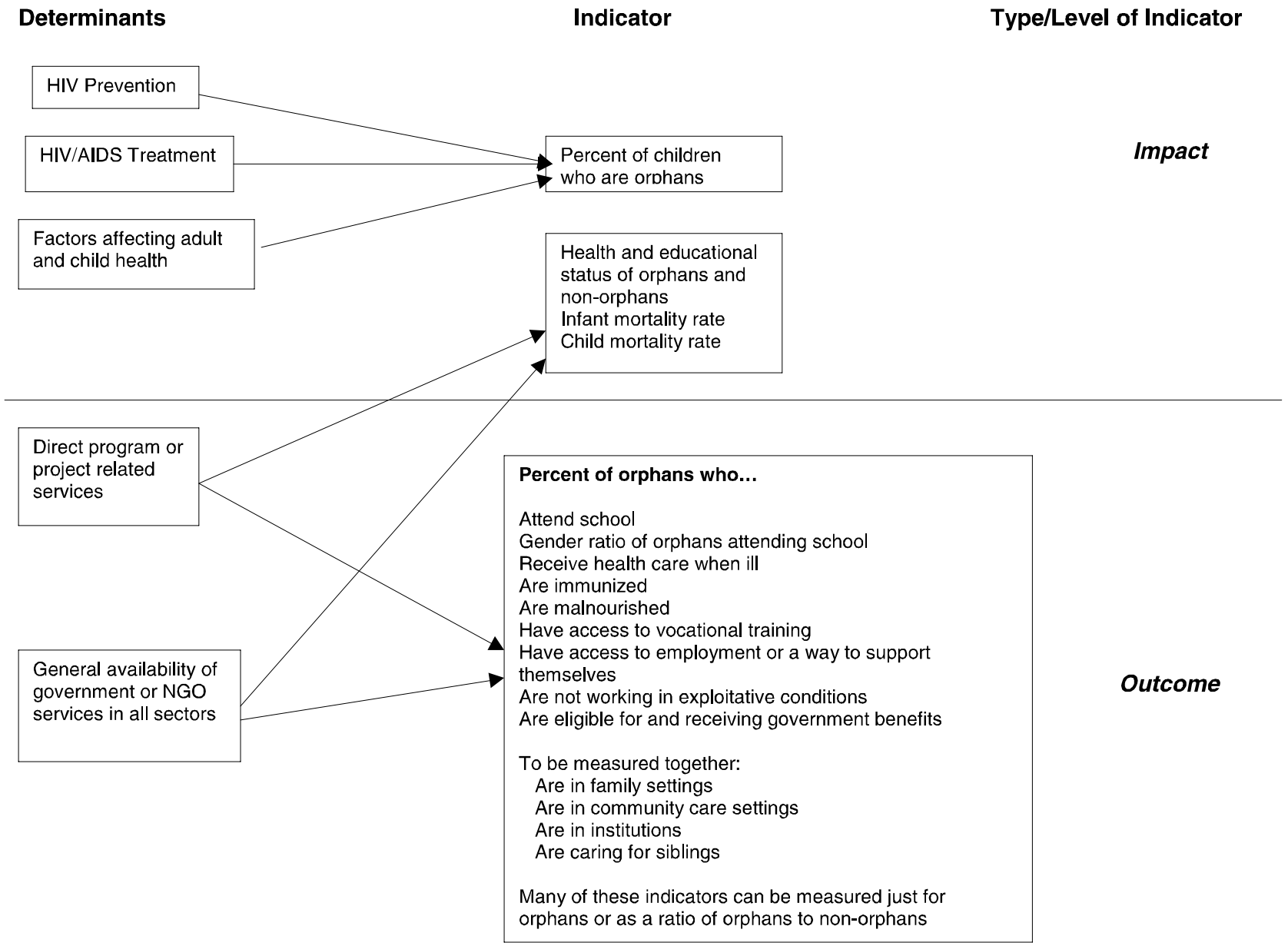
Output Indicators. Output indicators are measures of the result of project activities that affect the overall status of children, including policies and legal review; community development activities and programs; and provision of basic services. They also include the number of children, families or households and communities able to care for themselves or provide care and support for vulnerable children.

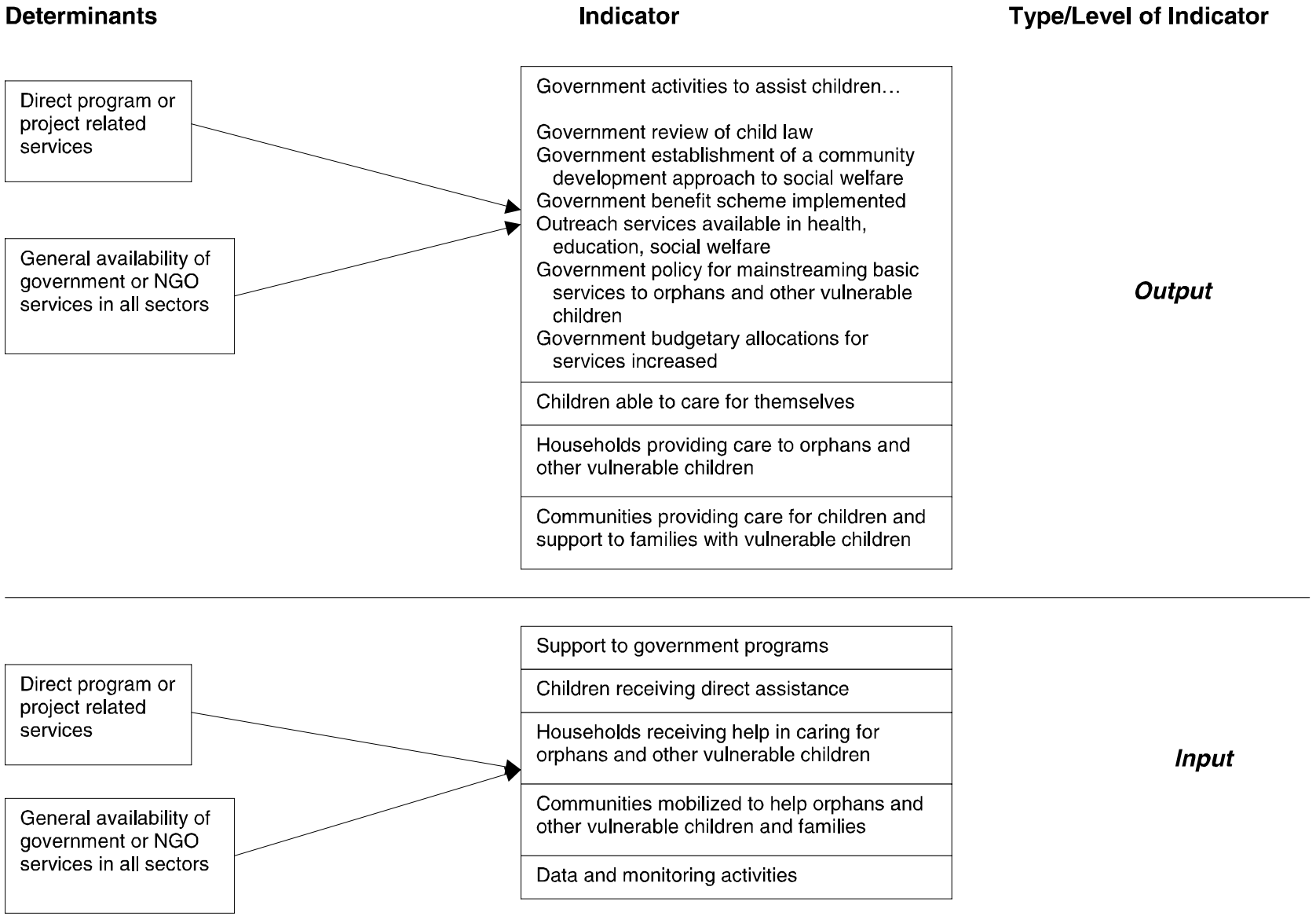
Input Indicators. Input indicators measure the resources put into project activities, and include the number of children, households, and communities receiving help and the support provided to government activities for assistance and policy review and revision.

Data for indicators. Data for indicators is available from a variety of sources depending on the level or type of indicator:

Impact. Demographic Health Survey (DHS), Dicennial Census or intercensal surveys
Outcome. DHS, censuses, special surveys, project data
Output. DHS, censuses, special surveys, project data, government data
Input. Project data, government data

DHS III, the current series of surveys, was redesigned in 1998 to survey children in all households, not just those in households with child bearing aged women. It is therefore more useful for comparing orphans and non-orphans than DHS II, but comparisons of these children require special tabulations of the household data and a commitment from the Mission to survey vulnerable children.


Determinants
Indicator
Type/Level of Indicator
HIV Prevention
HIV/AIDS Treatment
Factors affecting adult and child health
Percent of children who are orphans
Health and educational status of orphans and non-orphans
Infant mortality rate
Child mortality rate
Impact
Direct program or project related services
General availability of government or NGO services in all sectors
Percent of orphans who…
Attend school
Gender ratio of orphans attending school
Receive health care when ill
Are immunized
Are malnourished
Have access to vocational training
Have access to employment or a way to support themselves
Are not working in exploitative conditions
Are eligible for and receiving government benefits
To be measured together:
Are in family settings
Are in community care settings
Are in institutions
Are caring for siblings
Many of these indicators can be measured just for orphans or as a ratio of orphans to non-orphans
Outcome


Determinants
Indicator
Type/Level of Indicator
Direct program or project related services
General availability of government or NGO services in all sectors
Government activities to assist children…
Government review of child law
Government establishment of a community development approach to social welfare
Government benefit scheme implemented
Outreach services available in health, education, social welfare
Government policy for mainstreaming basic services to orphans and other vulnerable children
Government budgetary allocations for services increased
Children able to care for themselves
Households providing care to orphans and other vulnerable children
Communities providing care for children and support to families with vulnerable children
Output
Direct program or project related services
General availability of government or NGO services in all sectors
Support to government programs
Children receiving direct assistance
Households receiving help in caring for orphans and other vulnerable children
Communities mobilized to help orphans and other vulnerable children and families
Data and monitoring activities
Input

Notes

[1]Development of large-scale systems for impact mitigation is not an area for which there is a large body of written materials already on the shelf. Most of the published literature on orphans describes "micro level" project management: how the needs of children have been identified and the ways communities and families have met those needs. While these responses form the building blocks of large-scale systems development, the design and implementation issues faced at each level of a national system are very different.

As a consequence, the material on which this monograph is based is derived in large part from site visits and national assessments conducted in 1998 and 1999 in 12 Eastern and Southern African countries (Botswana, Kenya, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Uganda, Zambia and Zimbabwe), and an assessment visit in Haiti in 2000 (Hunter, all publications for 1998, 1999, 2000). Each assessment included a comprehensive review of the existing research conducted in the country on orphans. Other material is derived from the "micro level" experience of the author in developing community, regional and national programs (Hunter, 1989; Hunter, 1995). ***Reshaping Societies: HIV/AIDS and Social Change***, the author's new book (available from www.hudsonrunpress.com) expands on many of the themes contained in this paper.

[2] This chart was initiated during a workshop held at a meeting of UNICEF Child Protection Officers and counterparts from 15 countries in Nairobi in April 1999.

[3] This chart was initiated during a workshop with 73 UNICEF Child Protection Officers and counterparts from 15 countries in Nairobi in April 1999.

[4] A situation analysis may have been completed by UNICEF or an NGO. If not, ***Reshaping Societies*** describes procedures for conducting such an analysis, and also describes a step by step process for developing a national strategic plan based on the experience of heavily infected countries.

[5] ***Children on the Brink 2000*** provides estimates of orphans and a good description of methodology used for making the estimates.

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1300 Pennsylvania Avenue, NW
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